

End Of Life Care For Latino Patients In Rural East Tennessee: Do Patients Believe Their Cultural Differences Are Important?

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Citation

R Byington, L Grabner, S Keene. *End Of Life Care For Latino Patients In Rural East Tennessee: Do Patients Believe Their Cultural Differences Are Important?*. The Internet Journal of World Health and Societal Politics. 2008 Volume 6 Number 1.

Abstract

INTRODUCTION

Treating all patients with respect and love and with cultural sensitivity is an important aspect of healthcare. Healthcare providers must be mindful of differences in patient's culture, customs and traditions. In rural East Tennessee, there are several blends of cultures that have been part of the Appalachian culture for over two hundred years. In the two centuries immigration patterns for the United States brought more Europeans (Caucasians) to the rural landscape of Eastern Tennessee. As the descendents of early European settlers moved west of the Blue Ridge, their beliefs, customs and traditions became foundational and developed into the majority culture. The beliefs and customs of rural East Tennessee evolved from the majority culture and are based upon Biblical principles, Judeo-Christian theology, and Appalachian traditions and folklore.

As small family owned (subsistent) farms have slowly vanished and been replaced by larger (truck-style farms), the demand for farm laborers increased as the crop's harvest is readied. This change in agriculture, coupled with economic hardships for citizens of Mexico has created a new wave of immigration of Latino people into rural East Tennessee. As these two very different cultures blend together, healthcare providers are challenged and often struggle to provide culturally sensitive care. As these Latino immigrants come with dreams of a new home, career and families, they often become succumb to acute, chronic, and sometimes terminal illnesses. Because Latino's customs and language differ from the majority culture of East Tennessee, the need for treatment with regard to the unique heritage, customs, and traditions of the Latino patient takes on increased importance.

PROBLEM STATEMENT

In rural East Tennessee, the Appalachian culture has predominantly affected the way that end of life care for terminally ill patients has been provided. Healthcare providers do not receive culturally sensitive education and skills to help them understand the culturally differences present in the Latino population. The United States population demographics is changing. According to Blewett, Smaida, Fuentes, and Zuehike (2003) Latinos represent nearly 13% of the U.S. population, surpassing African-Americans as the nation's largest racial/ethnic group.

In East Tennessee, Washington County is one of the largest counties. According to P. B. Masters of the Washington County Tennessee Health Department, the city of Johnson City has a population of approximately 76,000, and Washington County an additional 46,000 people, with an estimated population of 4,000-5,000 migrant workers here in the Johnson City/Washington County area during peak farm season (personal communication, October 12, 2008). As these migrant workers serve these farming communities, they become ill with various acute, chronic and terminal illnesses. Their unique culture has different beliefs about end of life care. These differences include patient healthcare decisions made by the family as a whole, and not the patient by themselves. Therefore, there are several misconceptions and beliefs held by front line healthcare providers that are often fueled by their stereotyping and ignorance of cultural differences. As a result of these misconceptions and beliefs, a major impact on the quality of care of the terminally ill Latino patient may occur. This lack of cultural sensitivity could cause a significant negative impact on the quality of emotional, social, spiritual and even physical support given

by the healthcare provider. This research investigated whether healthcare providers in Washington County, Tennessee are providing culturally sensitive end of life care to the area's Latino population.

SIGNIFICANCE

The findings and conclusions of this qualitative study could refute or validate whether healthcare providers that are giving end of life care to the Latino population of the rural region of Washington County, Tennessee are doing so with regards to the beliefs, customs and traditions of the Latino culture rather than the beliefs customs and traditions of the majority culture. By sharing these findings, the general physical, emotional, social/spiritual, and mental healthcare needs of the Latino population could be addressed, and end of life care for the Latino patient could be improved. These findings could also serve as a springboard for other communities that are also challenged with the cultural differences and needs of the Latino patient and their families.

RESEARCH QUESTIONS

The following questions will guide the research:

1. What are the cultural beliefs, customs and traditions regarding end of life care of the Latino residents of Washington County, Tennessee and how are these beliefs, customs, and traditions exhibited during the care of Latino patients facing terminal illness and death?
2. By incorporating knowledge of the Latino culture regarding beliefs, traditions and customs of end of life and death can a significant impact be made on the quality of care that the terminally ill Latino patient receives in Washington County, Tennessee?

LITERATURE REVIEW

According to Diaz & Tellez-Giron (2005), the United States' Latino population is now the largest minority group, and there have been several studies done on the Latino dying patient. However, their study was conducted in areas with significant Latino populations such as the Mid-West, Florida, and California. No studies of end of life care were found that were specific to Latinos living in Tennessee, East Tennessee or in the rural Washington County.

The reality that Latinos are the largest minority group in the

U.S., along with the disparities faced by Latinos prompted Diaz & Tellez-Giron (2005), to highlight the need to promote research within the Latino population regarding their healthcare needs, policy making, program planning, and program implementation. One of the greatest barriers preventing the Latino patient from receiving culturally sensitive end of life care is that there is variation within the Latino population (Diaz & Tellez-Giron, 2005). According to the U.S. Census Bureau (2006), the term Latino (interchangeable with Hispanic) as used in this study is "A demographic and ethnic label to denote a group of individuals who share important cultural values". However, there are many subgroups within the Latino population, and include Puerto Ricans, Cubans, Central and South Americans, and Mexicans (Dingley, Roux, & Bush, 2000). Two of five Latinos are foreign-born, and many born in the United States adhere to customs from their country of origin. The cultural variability among Latinos can affect health behaviors. Thus, study of the need for routine assessment of the Latinos country of origin and its importance in providing healthcare is ongoing (Diaz & Tellez-Giron, 2005).

Some of the traditions of the terminally ill Latino patient are centered around strong spiritual beliefs of Catholicism (Dingley, Roux, & Bush 2000). According to their study of the inner strengths of terminally ill Latino female patients, "nurturing the spirit, spending time in prayer and connecting with others" was how these patients drew inner strength (p.32) . However Neubauer & Hamilton (1990) concluded that the male was the dominant presence in Latino families with regard to decision making, especially healthcare decisions. According to their study, the male also did not exhibit outward grief, but remained machoistic. The female patients in the study often felt that it was her duty to go on after living a long life, refusing any form of life support, while the male patient may feel that he is the head of household and thus no medical treatment should be withheld.

Duffy, Jackson, Schim, Ronis, & Fowler (2006) investigated the ethnic preferences for end of life treatment for the Latino patient and found that the Latino patient did not want a feeding tube, was against assisted suicide, and would consider alternative medicine. This study also showed that Latino patients were three times more likely than African Americans or Asians to want to die at home in the care of their family rather than in a long term care facility.

According to Purnell (1998), many healthcare decisions are

made in the context of culture and spirituality. This study of migrant workers who were dealing with end stage cancer found that some of the healthcare workers were not prepared to deal with the difference in beliefs of the Latino families. These cultural differences included animal sacrifice, wearing of a poultice filled with strong herbs or bones, or rooms filled with family members, some of them lying with the patient in bed. This study focused on the attitudes of the healthcare workers and on the feelings of the patient and families about the nursing care.

Kim-Godwin, Clarke, & Barton (2001) found that culture skills were defined as the abilities to conduct a cultural assessment, to communicate with clients, and to act as a cultural facilitator and advocate. Cultural abilities/skills enabled nurses to incorporate aspects of their client's cultural system, migratory life style and socioeconomic conditions in their care, leading to client satisfaction and increased utilization of health care services. The study found that without these cultural abilities/skills to integrate cultural and social context into care, nurses are unable to develop trust with the Latino patient and the patient often feared existing health services.

In the Kim-Godwin, et al.(2001) study, 21 variables of culturally sensitive care were evaluated. The top six were: ability to establish trust, ability to work with a bilingual interpreter, avoidance of stereotypes and generalization about client's culture, ability to speak according to the client's level of understanding, ability to use culturally sensitive strategies/material, and ability to recognize client's level of literacy, either in Spanish or English. These results suggested that the respondents highly value the role of interpreter and the importance of communication. Furthermore, this study showed that Latino clients preferred nurses to use Spanish without an interpreter. Hallenbeck (2001) found that Latino patients, especially Mexican American patients, considered nurses to be non-caring when they did not communicate in Spanish while giving care. These findings may be interpreted that the respondents may believe that language differences are substantial barriers to providing adequate nursing care, but that they believe that fluency in Spanish is different from Spanish speaking ability.

MAGNITUDE OF THE EMERGING PROBLEM

According to U.S. Department of Health and Human Services as quoted in Larson (2001), the migrant farm worker has one of the highest morbidity and mortality rates

in the United States. In 2000, their average life expectancy was 49 years, compared to the national average of 77.3 years. Many health problems suffered by farm workers are related to their occupation and substandard, overcrowded conditions, including dehydration, communicable disease, heat stroke, parasitic infections, digestive disorders, depression, musculoskeletal problems, respiratory problems and cancer (Larson, 2001).

According to the American Cancer Society (2006), an estimated 82,080 Latinos will be diagnosed with cancer in 2006, and approximately 12,232 will die from cancer. Latinos have higher morbidity rates and higher mortality rates from cancers of the stomach, liver, uterine, cervix, and gallbladder. According to a study by Morantz & Torrey (2003), these rates reflect greater exposure to specific infectious agents and lower rates of screening for cervical cancer, as well as dietary and possible genetic factors. Johnson, Kuchibhatala, Sloane, Tanis, Galanos, & Tulskey (2005) found that Latinos with terminal illness are underrepresented in Hospice care. It was not known whether this difference was due to cultural preferences for place of death or decreased access to hospice.

In summary literature concludes that Latinos in the U.S. feel that there is not always regard for their cultural practices, beliefs or ceremonies during end of life care. It was further noted that many Latinos recognize a feeling of nurturing and caring when their healthcare providers speak Spanish when treating them.

METHODS

An in-depth qualitative research study was necessary to evaluate the opinions of the area's Latino population as well as the practices of healthcare providers in Washington County Tennessee that provide care for the majority Caucasian population as well as Latino residents. The focus of this study was Latino patients that receive end of life care.

RESEARCH DESIGN

Ethnography was selected for this study. An ethnographic research design includes "the art and science of describing a group and its culture" (Bailey, 1997 p.138). The constructs of the culture of Latino patients is studied to first determine what important rituals, traditions and beliefs surround the patient and families dealing with end of life issues. These constructs include issues such as treatment, pain control and religious rites. Because the researcher or their representative served as this ethnography's data collection instrument, data

were collected in a manner that assured strict compliance with Health Information Portability and Accountability Act (HIPAA). HIPAA guidelines regarding patient confidentiality and privacy were followed and privacy was maintained.

PARTICIPANTS

The study's sample represents a purposeful sampling of Latino patients receiving end-of-life care for various terminal illnesses. Babbie (2008) described a purposeful sample as “a type of sampling in which the units to be observed are selected on the basis of the researcher's judgment about which ones will be the most useful or representative” (p. 520). The researchers selected twenty two patients (fourteen male and eight female) from a Blood and Hematology Center; eleven patients (seven male and four female) from a university based Cancer Center and five patients from Washington County Tennessee that were enrolled in outpatient care with physicians other than those practicing in the Blood and Hematology Center or the university based Cancer Center. An interpreter was present during data collection and she assisted with obtaining informed consent from the study's participants. She was familiar with the study, a breast cancer survivor, and has chaired a cancer support group for Latino patients in Johnson City/Washington County, Tennessee.

DATA COLLECTION PROCEDURES

Because one of the study's authors is an Oncology Certified Nurse, it was relatively easy to fit into the culture of the study's institution and oncology centers. During the data collection encounters, an interpreter well-known to the patients and their families because she lives in one of the largest Latino areas in Washington County introduced the researcher as a nurse who was interested in improving the end of life care for all of the terminally ill Latino patients in Washington County, Tennessee. The researcher was greeted warmly by the participants as they chatted with the interpreter in his or her own language and dialect. Minerva, the interpreter and key informant, explained in detail the reason for the researcher's presence and questions. Informed consent was obtained and the patients were eager to help someone else who may be suffering from like or similar illnesses.

Fieldwork visits were set up around the dates and times that patients came into the clinics for treatment or checkup. Initially, the fieldwork consisted of observation of the

clinical environment and the interaction between the providers and the patients. Interviews began as unstructured, but became structured as questions and then turned to open ended questions about the patient's specific culture and how terminal care was provided and end of life issues were addressed within the constructs of the patient's native culture. Because the interpreter was Latino and knew the specific dialects of the participants, the interpretations of the answers are more accurate and meaningful. As patients and families were asked questions centered around honoring their beliefs and culture by healthcare providers during end of life care, data concerning the study's central theme were collected.

Pacing of the interview allowed the patient and their families time to think about their feelings before answering. This additional time with each patient gave the researcher time to observe the interaction, voice inflections, and non-verbal communication during the exchange between the healthcare providers and the patients. Fieldwork notes, as well as interviews with patients and families, helped the researcher to develop a network of data that was used during the data analysis. Leaving the treatment/interview area was somewhat difficult as the researcher developed a relationship with the interpreter and the patients.

DATA ANALYSIS

According to Lincoln & Guba (1985), data analysis is done using patterns, categories, and descriptive units as ways to describe data and to deduce causes, consequences and relationships. As the interpreter asked the questions and interpreted, the researcher took detailed field notes, and used audio- tape to record the answers. The contents of the audio tapes were transcribed into Microsoft Word documents. Transcripts of the data and field- work were read and re-read line-by-line to derive concepts related to the participants' experiences. The experiences were then coded, grouped by their self-identified cultural and/or religious group and analyzed on a case-by-case basis to look for codes, categories and themes within that individual's experiences. The experiences were compared across the information derived in the literature review to look for similarities and differences in categories. Matrices were used to organize and collapse codes into categories.

Finally, the study's data were organized by description (using index cards) to help make interpretations of the collections of individual data elements. Next, the data were grouped by phrases, sentences and paragraphs that had

similarities. Categorizing the data that is consistent was the next step and then fleshing out threads of data by putting them into patterns lead to emerging themes that lead to the final product of content analysis.

FINDINGS AND CONCLUSIONS

FINDINGS

In the oncology environment of the Cancer Center, it was noted that most patients interacted in English and were on a first name basis with their nurses. However, when any information about effects of treatment or changes in regimen was communicated, translation into Spanish was needed.

The interview began with the question “What is it like in your culture when a family member dies?” Follow-up questions included:

- What does the immediate family do when a family member dies?
- What do friends and relatives do when a family member dies?
- What rituals or ceremonies are done for a family member who is dying?
- Are there any differences in rituals or ceremonies for adults or children when a family member is facing death?
- What meaning is attached to the death of an infant or child?
- Are there any spiritual or religious ceremonies that are done during the patient's terminal illness or immediately following their death?
- How long does the bereavement period last for the family members?
- How does religious affiliation affect what family members do and what is expected of them?

Participants described their feelings when talking to an interpreter instead of directly with the caregiver, their experiences with death, ritual, and ceremonies involving friends, families and religious leaders.

Group participants identified themselves by their own or their parents' countries of origin, their religious affiliations, and some as belonging to the large racial/ethnic group of

Latinos. They also spoke about the influence of European and Spanish colonies as well as Catholicism on their families' beliefs, ceremonies, rituals, and celebrations.

A persistent theme that emerged was that beliefs about the soul of the deceased lead families to perform rituals and ceremonies that foster passage to God, the light, or into another life. The stronger their beliefs, the more dedicated the families of the deceased are in completing the rituals and ceremonies of the religion or ethnic background. Participants did not practice some or all of their parents' or grandparents' rituals and did not know the meaning of certain rituals and ceremonies. Prayer was a consistent practice performed to ease the passage of the soul.

The beliefs of the time before death were that it was a time of preparation for death. Participants discussed the choice of visitors, preparation of the environment, and decisions to be made for a dying family member's wishes. Participants also described the practice of calling a priest for last rites when a loved one may be dying, although they might hesitate because this sacrament may somehow assure the death. Participants also described a need to do all that is necessary to keep the person alive. A Do Not Resuscitate Order (DNR) may not be signed unless the dying person is older because of their belief that older people should “gracefully accept death” (Lobar, Youngblut & Brooten, 2006, p.46). Participants also stated that no extra measures should be done for the elderly so that they “can die with dignity” (Lobar, Youngblut & Brooten, 2006, p.46). Participants do not like to discuss DNR orders because they do not want to take responsibility for pulling the plug or feeling great responsibility for the rest of the family saying that “he died because you killed him” (Lobar, Youngblut & Brooten, 2006, p.47).

None of the participants stated an affiliation with Santeria, which is a religion derived from a blend of Catholicism and folk medicine (Grossman, 1996). However, they had heard of family members who wanted to practice rituals using sacrifice, incense and perfumes. One participant noted that ceremonies and rituals using small birds, or more elaborate ceremonies using bigger animals are sometimes done in the home.

Participants discussed after death beliefs that if an infant dies, then they must be baptized as soon as possible, even if the parents have different beliefs. This ensures a safe passage for their soul. If the infant is not baptized, the soul

could remain in limbo.

Participants held the belief that all souls must be sent to heaven by prayer and holding mass for the deceased.

Participants discussed having several nights of mass following the death of a family member.

All of the participants in this study identified themselves as Catholic and they discussed how Catholic beliefs heavily influenced many of the beliefs, rituals and practices among their families during the dying process and after death. They also expressed a strong relationship between the living and the dead by having prayer and visits to the grave every year. Participants also discussed how healthcare providers who are not from a Catholic background do not understand the rituals and ceremonies of their families. Participants also discussed how they felt healthcare providers who did not take time to ask what their beliefs and rituals were before the family member was involved in the dying process were seen as uncaring.

CONCLUSIONS

During the structured interview process, some of the cultural beliefs that were deemed important by the participants in regard to end of life issues were having their priest visit to perform last rites, having family present in and outside the room, and allowing for special rites or sacraments of the Catholic religion. It was also suggested that it is important for the healthcare provider to show interest in the culturally different beliefs, rituals, and ceremonies during the end-of-life care of the Latino patient before death of the patient occurs. This research also suggested that it is important to the participants that the healthcare provider learns to speak Spanish. Native language speakers were perceived as more caring and exhibited concern for the patient. Latino participant's ceremonies are important steps that help the patient and the family has peace with the dying process and death. This research also suggests that these are also times when understanding and even involvement of the healthcare provider can foster better relationships and a higher quality of care for the Latino patient and the patient's family during the difficult stage of end of life care.

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